DOCUMENT RESUME

ED 344 398 EC 301 127

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TITLE Permanency Planning for Children with Developmental Disabilities. Executive Summary.
SPONS AGENCY Colorado Developmental Disabilities Planning Council, Denver.
PUB DATE Oct 90
NOTE 15p.
PUB TYPE Reports - Research/Technical (143) -- Viewpoints (Opinion/Position Papers, Essays, etc.) (120)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Agency Cooperation; *Agency Role; Children; *Decision Making; Delivery Systems; *Developmental Disabilities; Influences; *Long Range Planning; Parent Attitudes; *Placement; Program Development; *Residential Programs; Respite Care
IDENTIFIERS Case Management; Colorado; *Permanency Planning (Foster Care)

ABSTRACT

This report discusses issues regarding the out-of-home placement of children with developmental disabilities and the need for permanency planning for these children. The document reports on a project which sought to: (1) discern practices of Colorado's Department of Social Services and Division for Developmental Disabilities which affect the out-of-home placement of children with developmental disabilities; (2) determine parental perceptions of factors that lead to caring for their children in or out of their homes; and (3) make recommendations for necessary systems changes. The project interviewed 51 parents and 53 case workers, case managers, and social workers concerning 131 children placed in group homes or regional centers. Forty families who kept their child with disabilities at home and 12 families of adopted children with developmental disabilities were also interviewed. Findings are reported in terms of system issues, children's issues, families' issues, and case workers' or case managers' issues. Among the findings were the following: agency roles and responsibilities have not been clearly defined; many services are not effectively publicized to parents; interagency coordination, communication, and cooperation need improvement; respite care was the number one support needed by all families; and permanency planning was not well understood nor practiced by case workers or case managers. Recommendations for change are also provided. (JDD)

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PERMANENCY PLANNING FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES

EXECUTIVE SUMMARY

Prepared For The
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Mary Erickson

October 1990

**The data in this report was collected between March and October 1989.

BACKGROUND AND PURPOSE OF THE STUDY

This project was the result of several initiatives developed by the Colorado Developmental Disabilities Planning Council (CDDPC) that raised major issues regarding the out-of-home placement of children with developmental disabilities and the need for permanency planning for these children. The purpose of this project was multifaceted: 1) to discern current practices of the Department of Social Services (DSS) and the Division for Developmental Disabilities (DDD) which affect the out-of-home placement of children with developmental disabilities; 2) to determine parental perceptions of factors that lead to caring for their children in or out of their homes; and 3) to make recommendations for necessary systems changes.

The Council formed a Permanency Planning Task Force whose members represented public and private agencies, state and county DSS, the state office of the DDD, community centered boards (CCBs), advocacy organizations and parents of children who have developmental disabilities. Two staff members were hired in order to complete the study in the next 18 months. The task force formulated several questions to which evident answers were not available:

1. Will the DSS system or the DDD system serve and be responsible for children with developmental disabilities?
2. How are children to be served?
3. How much does this service cost?
4. How are these costs to be paid?
5. Where can parents turn for assistance with their child who has a developmental disability?

The task force also wanted more information on issues and barriers that prevent successful permanency planning for children with developmental disabilities. These issues fell into four major categories: philosophical differences; fiscal restraints; structural bifurcation; and inadequate delineate of jurisdiction. Other issues of concern were: 1) Why are some families able to keep their child with developmental disabilities at home? and 2) Why do some families adopt a child with developmental disabilities?

The following statement was adopted by the Task Force in March 1988 and amended in April 1990. It provides a values base for services to families and children.

> "A Statement In Support Of Families And Children," (adapted from a Statement in Support of Famiilies and Children from the Center on Human Policy, June 1986.)
>
> Every child shall have the right to a permanent home and a stable relationship with one or more adults.
>
> I. Families shall receive the supports necessary to maintain their children at home.
>
> II. Family supports shall build on existing social networks and natural sources of support.
>
> III. Family supports shall maximize the family's control over the services and supports they receive.
>
> IV. Family supports shall be available for the entire family.
>
> V. Family support services shall encourage the integration of children with disabilities into the community.
>
> VI. When children are without families, adoption shall be aggressively pursued.

DEFINITION AND COMPONENTS OF PERMANENCY PLANNING

"Permanency planning is first a philosophy. It is a way of thinking about and valuing children and families" (Taylor et al., 1989, p. 546). Every child, including a child with developmental disabilities, has the right to a permanent home and a stable relationship with one or more adults. A stable, consistent family environment that provides nurturing, support, safety and love with long-term attachments provides the

greatest opportunity for a child to grow and learn during the time limited years of childhood. In addition a child with developmental disabilities often needs a life-long advocate and a family that is invested in its child with disabilities can be that advocate.

There are several essential components of successful permanency planning. In order for a child to live at home, the family must have adequate support. If a child is already in out-of-home placement, every effort must be made to reunite the child with his/her family. When the return home is not possible the solution most in keeping with the principle of permanency planning would be that the process of termination or relinquishment of parental rights would commence so that the child could be freed for adoption. However, in Colorado, there are not sufficient supports and resources available to families to enable them to keep their child at home. Services are fragmented and there is not a comprehensive approach across agencies.

When it is not possible for a child to live with his/her birth family or when adoption is not feasible, other options need to be explored. A critical component when implementing the permanency planning process is that each family and child's situation is assessed individually, taking into account the uniqueness of each family's circumstances. The ultimate goal of permanency planning is a plan that is written, that is time-limited, and that can ensure that the child will grow up in a family.

METHODOLOGY

Five counties, Adams, Denver, Mesa, Montrose, and Weld, representing both urban and rural populations, were selected for the in-depth study of children with developmental disabilities who were placed out-of-home through DSS or through their regional CCB. Print-outs from Client Oriented Record Entry (CORE) at DDD and from Child Welfare Eligibility Tracking (CWEST) at DSS were used to determine the number of children in placement. Forty children from these five counties had currently been placed in group homes through CCBs and 19 had been placed into Regional

Centers (RC). All 59 of these children were chosen for review. Since DSS had a larger population to consider, a random sample of 89 children were chosen from the five counties. Of the 148 chosen for review, the actual total of children reviewed was 131.

Questionnaires containing both open-ended and forced answer questions were developed by the project staff and the task force. Fifty-three case workers, case managers, and social workers, representing each child chosen for review were interviewed face to face, and the child's file was also reviewed.

Letters explaining the study and requesting an interview were sent to the parents of the 131 children chosen for review. A follow-up phone call was made to determine if the family would consent to an interview. One parent refused the interview because of health problems; seven parents made appointments and did not keep them; 12 parents living out of state were not contacted; 30 parents had had their rights terminated or had relinquished their rights and 30 parents were unreachable by letter or by telephone. Fifty-one (39%) of the families were interviewed face to face. Forty-seven were biological parents and four were adoptive parents.

One of the members of the task force who is a parent provided a list of names of parents who have kept their child at-home and who were willing to be interviewed. These parents were not sent a letter but were contacted by telephone to set up an interview. Several parents interviewed mentioned other parents who would also be willing to be interviewed. This was not a random sample but was felt to be fairly representative of parents who have kept their child at-home. Forty of these families were interviewed face to face.

A task force member also supplied the names of families who have adopted children with developmental disabilities. These families were contacted by telephone and interviews scheduled. Twelve families who have adopted a total of 18 children were interviewed. This was also not a random sample, but again, is felt to be representative.

To get an understanding of each agency and its operation, the director of each CCB and county DSS was interviewed by telephone. These interviews contained only open-ended questions.

SIGNIFICANT FINDINGS AND CONCLUSIONS

SYSTEMS' ISSUES

No state agency is solely designated to serve children with developmental disabilities nor have agency roles and responsibilities been clearly defined.

C.R.S. 26-1-102 states that DSS is responsible for "child welfare services, child care and protective services for mentally retarded." C.R.S. 27-10-5 states that CCBs are the designated agencies responsible for the determination of eligibility and the development of an Individual Habilitation Plan (IHP). This, however, does not entitle individuals (children or adults) to services. This study indicates that collaboration between the two major systems, DSS and DDD, is needed and these agencies must determine which system will provide which services to these children. The two systems working together can maximize support to families and children by coordinating efforts and resources.

The exact number of and statistics about children with developmental disabilities in Colorado are unknown.

The DSS and DDD computer systems each use their own method for describing a child receiving services. Another problem in both systems is that the handicapping conditions of the children listed in their files or stated by their case workers/case managers, do not always match the conditions listed on the CWEST and CORE printouts. To remedy the situation, the following things need to happen: DSS and DDD must work together to develop the descriptive categories for children, the descriptive categories must be prioritized according to a uniform plan, workers must be trained in how to use the system, information must be entered and updated in a timely manner, and the computer description of each child must match the child and be the

same as the description in the child's file.

Interagency coordination, communication and cooperation need improvement.

Within a county, the interviewed workers in DSS and managers in CCBs seldom knew each other and often did not understand one another's jobs. Nor were these workers aware of what services were offered by the other agency or how to access the other system. Four interagency teams formed during the Permanency Planning Training Project were evidence of the benefits of cross-agency sharing for children and their families.

Many services within the systems are not effectively publicized to parents.

Parents spoke of the constant struggle they encountered when trying to find services for their children. They reported that unless they asked a specific question about a service, the information was not volunteered to them. Resources are so limited for families and children that combined efforts, with open sharing of information among professionals and parents, must be encouraged and designed to happen.

Services are not currently available to all persons with developmental disabilities who request them.

Once a child is identified as having a developmental disability, that child will most likely need some level of service throughout his/her life. Most CCBs have extensive waiting lists of persons with developmental disabilities needing services. Therefore, the state must acknowledge this need and develop a comprehensive plan, with time-limited goals and objectives, to address the availability of life-long services to persons with developmental disabilities, thus eliminating the need for waiting lists.

CHILDREN'S ISSUES

A child's handicapping condition does not determine where the child will live.

Children with all levels of mental retardation, including those requiring intensive, 24-hour care, lived in all three settings: out-of-home placement, biological family home

and adoptive home. More children placed through DSS functioned in the mild or moderate mental retardation range and had emotional/behavioral problems, while the majority of children placed through the CCBs and RCs functioned in the profound range. The long-held assumption that the more severely involved, difficult-to-care for children are placed out-of-home and are not adoptable was not proven by this study.

A large group of children had medical needs that required intensive, 24-hour care.

Some parents are able to care for their children with intensive medical needs at home. A few medical foster homes are also now available and can provide the necessary care, so children with these needs no longer have to live in Regional Centers. However, there are not enough of these medical foster homes available for the numbers of children who need them. The state must actively develop more medical foster homes as an alternative to group homes or institutions.

Once children with developmental disabilities were placed out-of-home, they were likely to remain in placement throughout childhood.

According to the Colorado Foster Care Study completed in February 1989, the average length of time all children were in placement in Colorado was 8.5 months. For children with developmental disabilities in this study, 7.3 years was the average length of time in placement!

Not only are children with developmental disabilities placed out-of-home for a longer time, many of them experience multiple placements. Of the 131 children in the study 43 had four or more placements, with the maximum number being 23 for one child. Some children suffered multiple placements in one year. Although 34 of the children studied had only one placement, most of them were in congregate care facilities, without the benefit of family life and without assurance that they would not be moved. A viable permanency plan for each child in placement is necessary.

Children with behavior problems were moved from one placement to another in response to their behaviors.

"Child's behavior problems" was the reason given most often for children's change

of placement. Families of children with behavior problems need both intervention and support at the onset of behaviors. Early intervention might have prevented an exacerbation of the problems that ultimately led to multiple placements.

FAMILIES' ISSUES

Results were inconclusive regarding why parents do or do not place their child out-of-home.

The study indicated that parents who kept their child at home generally had a lower average age, higher average household income and more college education than did the parents who placed their child out-of-home, or parents who adopted a child with developmental disabilities. Although interesting, these characteristics are not necessarily the reasons for choices made. Noteworthy was that 13% of the parents who had their child at-home were single parents, while other single parents stated this as their reason for placement. Families stated that services must be designed to address their individual needs.

Barriers to the child's return home, from the families' point of view were:

- Some did not want their child to return home.
- Some needed support in order for their child to return home.
- Children in placement who were over 16 years old, needed to remain there so they would not lose their residential slot. Parents found that children in placement prior to age 16 were assured of residential placement as an adult. Parents who kept their child at home until age 18 or 21 had a more difficult time securing adult residential placement.
- Some children's behaviors were too destructive and dangerous for them to live at home.

Barriers need to be addressed for the child without a permanency plan who does not live at home. If the family does not want the child at home, a dialogue needs to take place between the family and the worker/manager regarding the child's future.

Respite care was the number one support needed by all families.

Affordable, quality respite care that is always available would allow some children to return home from placement. Much of the 24-hour stress of caring for a child with developmental disabilities could be alleviated with sufficient respite care.

More adoptive homes for children with developmental disabilities are needed.

Most of the children were adopted by families who knew them before the adoption. Creative ways need to be devised so that children who need adoptive families are exposed to many families in many different settings. Unfortunately, most county DSS have not included a specialist on their staff to recruit adoptive families.

CASE WORKERS'/CASE MANAGERS' ISSUES

Several factors that affected job performance were noted:

- 60%of the workers/managers had no college or university courses in developmental disabilities or special education.
- Workers/managers had been in their jobs an average of 1.2 years.
- Average caseload size was very high:

  29 families in DSS per worker

  62 children and adults with developmental disabilities in CCBs per case manager

  73 children and adults with developmental disabilities in RCs per worker

DSS workers mentioned the concern that they constantly responded to crises and felt they could offer only a "band aid" approach to their jobs, because preventive services are not mandated by DSS.

Permanency planning was not well understood nor practiced by case workers/case managers.

The DSS system was very aware of permanency planning and theoretically, all workers have had training in the concept of permanency planning, while the case workers/case managers in the CCBs and RCs have not had the training. Accurate

definitions of permanency planning were given by 45% of the DSS workers; 33% of the CCB managers; and 70% of the RC workers. For those who provided an accurate definition of permanency planning, the actual practice was inconsistent or completely lacking. For example: "continue placement," "move to adult placement," or "move to less restrictive environment" ("less restrictive" meaning to another placement, not to move home) were the permanency plans for 50% of the children served by the DSS, for 88% of the children served by the CCBs; and for 85% of the children served by the RCs.

Permanency plans also need to be time-limited. Only three workers in DSS mentioned a time limit in their definition, and very few of the children's files showed time-limited plans.

Furthermore permanency planning cannot happen for children in placement when case workers/case managers explained 60% of the children's current placements by saying, "The child was already in this placement when I received the case." Children were also not moved from current placements because they were "doing fine."

OTHER ISSUES

A possible source of increased revenue was noticed during this study.

Children with developmental disabilities placed out-of-home through DSS are eligible to receive Social Security Income (SSI) payments. Information from CWEST showed that only 48% of the children were receiving SSI. The loss of revenue for one year was estimated, by the analyst, at $600,000. The 48% may not be an accurate number because of the inaccuracy of CWEST data. A review of the system may be in order to determine how children are identified and become eligible for SSI payments.

RECOMMENDATIONS FOR CHANGE

The following recommendations are a composite of issues discovered by the research data and issues presented by task force members. The suggested changes do not need to be perceived as massive, immediate need for change, but can be accomplished in increments.

I. Permanency Planning Needs

A. Establish statewide technical assistance teams that are trained in permanency planning, to work with authority across systems' boundaries, for children with developmental disabilities with the following goals:

- o Review out-of-home placement
- o Recommend family support resources
- o Ensure permanency planning for every child
- o Provide training to all systems personnel, especially to judges, other court personnel, community centered boards, regional centers, social services, educators, health and hospitals

B. Require CWEST, the DSS computer information system, and CORE, the DDD computer information system, to have pertinent, timely information.

C. Identify workloads that are feasible for meeting family needs and fund adequate personnel (case workers and case managers) to achieve this workload level.

D. Establish a state-wide position for an adoption/foster care recruitment specialist for children with developmental disabilities.

E. Ensure there is a person with expertise in developmental disabilities as a member of the DSS Foster Care Review Design Team from its inception.

F. Ensure there is a judge on the Permanency Planning Task Force.

G. Require value-based interagency training for case workers, case managers, social workers, and foster parents on permanency planning for children with developmental disabilities.

II. Family Support Needs

A. Institute a comprehensive family support system, with financial assistance, to keep a child with developmental disabilities in his/her permanent family.

B. Establish a Home Community Based-Developmental Disabilities (HCB-DD) Waiver to provide in-home support for children with developmental disabilities.

C. Identify workloads that are feasible for meeting family needs and fund adequate personnel (case workers and case managers) to achieve this workload level.

D. Increase funding for the accessibility of and adequate staff support for the following family support programs at DSS and DDD.

DSS:

1. Katie Beckett Waiver
2. Special Needs Day Care
3. Home Care Allowance
4. Placement Alternative Commission (PAC) programs specifically for children with developmental disabilities
5. Private duty nursing
6. Adoption subsidy that includes special needs allowance; maintenance of Medicaid; is standard across the state; and abolishes the annual review
7. Services to children with challenging behaviors and/or psychiatric involvement
8. Respite care and training for the providers.

DDD:

1. Family Resource Services Program
2. Special Needs
3. Services to children with challenging behaviors and/or psychiatric involvement
4. Respite care and training for the providers

E. Establish and fund a few demonstration projects in alternative kinds of parenting for a child with developmental disabilities, i.e., co-parenting, shared parenting.

III. Revise and Enhance These Existing Services

A. Include the state definition from C.R.S. 27-10.5 of developmental disabilities in the DSS Staff Manual Volume 7, and train workers to use it.

B. Require CWEST and CORE to use the same descriptive categories for children with developmental disabilities; and to prioritize the categories in the same manner.

C. Develop methods for increased utilization of SSI.

D. Require a decision to be made about responsibilities for children with developmental disabilities, who are 16-21 years old, and are in the following circumstances:

a. Currently receiving services from DSS and will need a transition plan in order to receive services from DDD.
b. Enter either the DSS or the DDD system between the ages of 18 and 21.

E. Develop a single point of entry into the DSS system.